

Conducting qualitative research on cervical cancer screening among diverse groups of immigrant women

Research reflections: challenges and solutions

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ABSTRACT

OBJECTIVE To explore the research lessons learned in the process of conducting qualitative research on cervical cancer screening perspectives among multiple ethnolinguistic groups of immigrant women and to provide guidance to family medicine researchers on methodologic and practical issues related to planning and conducting focus group research with multiple immigrant groups.

DESIGN Observations based on a qualitative study of 11 focus groups.

SETTING Hamilton, Ont.

PARTICIPANTS Women from 1 of 5 ethnolinguistic immigrant groups and Canadian-born women of low socioeconomic status.

METHODS We conducted 11 focus groups using interactive activities and tools to learn about women's views of cervical cancer screening, and we used our research team reflections, deliberate identification of preconceptions or potential biases, early and ongoing feedback from culturally representative field workers, postinterview debriefings, and research team debriefings as sources of information to inform the process of such qualitative research.

MAIN FINDINGS Our learnings pertain to 5 areas: forming effective research teams and community partnerships; culturally appropriate ways of accessing communities and recruiting participants; obtaining written informed consent; using sensitive or innovative data collection approaches; and managing budget and time requirements. Important elements included early involvement, recruitment, and training of ethnolinguistic field workers in focus group methodologies, and they were key to participant selection, participation, and effective groups. Research methods (eg, recruitment approaches, inclusion criteria) needed to be modified to accommodate cultural norms. Recruitment was slower than anticipated. Acquiring signed consent might also require extra time. Novel approaches within focus groups increased the likelihood of more rich discussion about sensitive topics. High costs of professional translation might challenge methodologic rigour (eg, back-translation).

CONCLUSION By employing flexible and innovative approaches and including members of the participating cultural groups in the research team, this project was successful in engaging multiple cultural groups in research. Our experiences can inform similar research by providing practical learning within the context of established qualitative methods.

EDITOR'S KEY POINTS

- Research that informs core functions of the health care system, such as screening, must reach across diverse populations. This paper is a reflection of what research lessons were learned in the process of conducting a qualitative research study of cervical cancer screening perspectives among multiple ethnolinguistic groups of immigrant women.
- The researchers found that it was important to build community partnerships and include members of the groups of interest on the research team. Flexibility was needed when obtaining written consent and for inclusion criteria, which might be affected by cultural norms, and also for timelines, as each cultural group represented in many ways the start of a new process. Innovative strategies and interactive activities (such as indirect questioning, a drawing exercise, and a question-and-answer period with a female physician) helped to increase comfort and participation.

This article has been peer reviewed.
Can Fam Physician 2010;56:e130-5

Étude qualitative sur le dépistage du cancer du col chez divers groupes d'immigrantes

Réflexions engendrées par la recherche : défis et solutions

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RÉSUMÉ

OBJECTIF Dégager les leçons tirées d'une recherche qualitative sur le dépistage du cancer du col chez plusieurs groupes ethnolinguistiques d'immigrantes, et proposer aux chercheurs en médecine familiale des solutions aux questions pratiques et méthodologiques soulevées par la planification et la conduite d'une recherche utilisant des groupes de discussion avec plusieurs groupes d'immigrants.

TYPE D'ÉTUDE Observations tirées d'une étude qualitative de 11 groupes de discussion.

CONTEXTE Hamilton, Ont.

PARTICIPANTES Des femmes d'un des 5 groupes ethnolinguistiques d'immigrantes et des femmes d'origine canadienne de statut socioéconomique faible.

MÉTHODES Nous avons tenu 11 groupes de discussion à l'aide d'activités interactives et d'outils pour connaître l'opinion des femmes sur le dépistage du cancer du col, et nous avons utilisé comme source d'information sur le processus d'une telle recherche qualitative les réflexions de l'équipe de recherche, l'identification délibérée des préjugés ou des biais potentiels, un feedback précoce et continu de la part de travailleurs sur le terrain représentatifs des réalités culturelles, des débriefings post-entrevue et des débriefings de l'équipe de recherche.

PRINCIPALES OBSERVATIONS On a tiré des leçons dans 5 domaines : créer des équipes de recherche efficaces et des partenariats communautaires; trouver des façons appropriées d'évaluer les communautés et de recruter des participants; obtenir un consentement éclairé écrit; utiliser une façon délicate et innovatrice de recueillir les données; et gérer le budget et les contraintes de temps. Parmi les éléments importants, mentionnons l'implication précoce, le recrutement et la formation des travailleurs du domaine ethnolinguistique à la méthodologie des groupes de discussion, ces derniers étant les intervenants-clés pour la sélection et la participation des participants, et pour l'efficacité des groupes. Les méthodes de recherche (p. ex. modes de recrutement, critères d'inclusion) ont dû être modifiées pour s'adapter aux normes culturelles. Le recrutement a été plus lent que prévu. L'obtention du consentement signé pourrait aussi demander plus de temps. Les nouvelles façons de faire dans les groupes de discussion ont favorisé des discussions plus intéressantes sur des sujets délicats. Le coût élevé de la traduction professionnelle pourrait aussi constituer un défi pour la rigueur méthodologique (p. ex. la retraduction).

CONCLUSION Par son approche flexible et innovatrice, et l'inclusion dans l'équipe de recherche de membres des communautés culturelles participantes, ce projet a réussi à amener plusieurs groupes culturels à participer à la recherche. Les leçons pratiques tirées de l'étude peuvent être utiles à des études semblables portant sur des méthodes qualitatives établies.

POINTS DE REPÈRE DU RÉDACTEUR

- Une recherche portant sur les fonctions de base du système de santé, telles que le dépistage, doit inclure plusieurs types de population. Cet article est une réflexion sur ce que nous a appris la conduite d'une étude qualitative sur le dépistage du cancer du col chez divers groupes ethnolinguistiques d'immigrantes.
- Les chercheurs ont observé l'importance de créer des partenariats communautaires et d'associer des membres des groupes d'intérêt à l'équipe de recherche. On a dû faire preuve d'une certaine flexibilité pour l'obtention du consentement écrit et pour les critères d'inclusion, lesquels pouvaient être influencés par les normes culturelles, et aussi pour les contraintes de temps, puisque que chaque groupe culturel représentait en quelque sorte le début d'un nouveau processus. Des stratégies innovatrices et des activités interactives (telles que des questions indirectes, un exercice de dessin et une période de questions-réponses avec un médecin) ont favorisé le confort et la participation.

Cet article a fait l'objet d'une révision par des pairs.
Can Fam Physician 2010;56:e130-5

Research that informs core functions of the health care system, such as screening, must reach across a very diverse population. Qualitative research methods have long been used in the social sciences; however, use of these methods in family medicine research is newer.¹ Qualitative studies about cervical cancer screening in immigrant women tend to include a single ethnolinguistic group and, although this research has studied perceptions and behaviour around cancer screening in general, there is less known about which research approaches are effective in multiple immigrant groups, in particular for cervical cancer screening.

Immigrants are often underrepresented in clinical research.^{2,3} Working with immigrant groups poses challenges related to accessing and gaining the trust of potential participants, as well as understanding language and cultural differences. Within these broad approaches, there are specific strategies that researchers can employ to create knowledge that will assist health care providers and planners in better understanding health-related views and experiences of immigrant groups.

This paper provides guidance to family medicine researchers on methodologic and practical issues related to planning and conducting focus group research with multiple immigrant groups. We describe what was learned in the process of conducting a qualitative research study of 5 ethnolinguistic groups on their perspectives on cervical cancer screening.

METHODS

We used team reflections, deliberate identification of preconceptions or potential biases, early and ongoing feedback from field workers, postinterview debriefings, and research team debriefings as sources of information to inform the process of conducting qualitative research with multiple groups of immigrant women.

Our observations are based on a qualitative study of cervical cancer screening with 5 ethnolinguistic groups of immigrant women and 1 Canadian-born group of low socioeconomic status in Hamilton, Ont. The study was approved by the Hamilton Health Sciences/McMaster University Faculty of Health Sciences Research Ethics Board.

We conducted 11 focus groups using interactive activities and tools to learn about women's views on cervical cancer screening. The study aimed to explore perspectives on cervical cancer and screening in multiple ethnolinguistic groups to inform both broad and group-specific strategies for increasing uptake of screening in order to prevent cervical cancer. Participants are described in Table 1. In the focus groups we sought women's views about health care-seeking behaviour, cancer awareness, and cervical cancer specifically, including causation, risk

factors, prevention, pathophysiology, outcomes, and treatment. We also used several interactive activities and approaches, which are listed in Table 2.

Table 1. Overview of focus groups*		
FOCUS GROUP	LANGUAGE OF FOCUS GROUP	ETHNOLINGUISTIC GROUP
1	English	Canadian-born, low socioeconomic status
2	English	Arabic
3	Arabic	
4	English	Chinese (Cantonese)
5	Cantonese	
6	English	Somali
7	Somali	
8	English	Afghani
9	Dari	
10	English	Latina (Central American)
11	Spanish	

*The interview guide was field-tested with a group of English-speaking, Canadian-born women.

Table 2. Focus group processes and activities	
SEQUENCE	PROCESS OR ACTIVITY
1	Welcome and dinner for participants and their children
2	Introductions, written consent, description of focus group, and ground rules
3	Questions about an imagined friend
4	Anatomy drawing exercise
5	Show Pap test video, lead discussion on content and suitability of video
6	Handle and discuss self-sampling kit for human papillomavirus
7	Final comments and collection of postinterview information
8	"Doc talk" (female GP joins group to explain anatomy, cervical cancer, and screening, and to answer participants' questions)

FINDINGS AND DISCUSSION

Forming an effective research team and building community partnerships

The interdisciplinary research team included family physicians, a medical anthropologist, a sociologist, a pathologist, experienced qualitative researchers, and field workers recruited from each ethnolinguistic group.

Collaboration with a local immigrant settlement agency, the Settlement and Integration Services Organization (SISO), enabled us to enrol participants from diverse groups in the community. Authorization

for the partnership was given by the executive director of the agency. Two of the researchers had a previously established relationship with the organization. Through SISO, we identified potential field workers and recruited participants. Linking with an established community-based organization that had strong ties to the target participant groups was critical to the success of the project because this became the central “node” for interaction with potential participants. Other researchers have also found that establishing trust with community organizations that serve the population of interest aids in recruiting people from ethnic minority groups.^{4,5}

Bilingual field workers recruited from each of the selected ethnolinguistic groups brought essential cultural knowledge to the study; however, they also required practical training in research principles, participant recruitment strategies, and qualitative interviewing techniques. They were included in the research team early and participated in 2 to 3 dedicated training sessions with the methodologist, using the interview guides developed for their particular groups. Training included how to identify eligible participants and explain focus group interviews to them; obtain informed consent; co-facilitate focus group interviews in English; and later facilitate group interviews in their own first languages (including encouraging participation by all group members, using probes to obtain more in-depth information, and collecting postinterview demographic information from participants).

Accessing communities and recruiting participants

For each ethnolinguistic group, we conducted 2 separate focus groups: one in English and the other in the first language of participants. Two separate focus groups were done to assess the effects of culture alone and then to assess the effects of culture and language together. Some of the immigrant women with good English-language skills still preferred to participate in the native-language groups. We also included a group of English-speaking, Canadian-born women of low socioeconomic status, in part to test the interview guide and focus group processes, as well as to assess the effects of socioeconomic status, independent of ethnicity, on key research questions.

During this study, we learned that inclusion criteria might need to change for reasons of cultural appropriateness. For example, field workers advised us that because of cultural and religious norms, it might not be appropriate to invite unmarried women to discuss sexual health issues, particularly if the group also included married women; thus, eligibility criteria were altered to include married women only. We also loosened the original requirement for the maximum number of years living in Canada of 5 because of difficulty recruiting newer immigrants in some groups. Participants often

preferred to come with a friend or relative who had been in Canada longer, and we welcomed all attendees in the spirit of hospitality that our field workers advised us would be beneficial to recruitment. Although these recruitment methods and the snowball technique might have resulted in groups comprising more acculturated and less representative women, they were essential to ensuring participation.

Our initial strategy of placing recruitment posters in strategic locations, such as community centres and places of worship, did not elicit any responses. The most effective strategy was recruitment by word of mouth, using the snowball technique to reach additional women through each contact, as well as face-to-face contact and scripted telephone calls by field workers and SISO employees who had well established roles in their ethnolinguistic communities. This supports the overall consensus in the literature that many minority groups respond favourably to direct, personal appeals from known individuals as a recruitment strategy.⁶⁻⁸ There was also a need to respect different gender roles and expectations in some of the ethnolinguistic groups; some women’s husbands were “gatekeepers,” speaking with the field workers to ascertain the purposes of the groups, and giving their consent with the condition that their wives be picked up from home or accompanied by a friend or relative.

As reported in other studies, we found that ethnoracial and linguistic differences between the researchers and the participants were not a barrier to research because of steps taken to ensure cultural appropriateness in our recruitment strategies, interview guide development, and hospitality at the focus groups.⁹ Without the direct involvement of members of the selected ethnolinguistic groups to serve as field workers, however, we would not have known about culturally appropriate methods of securing the trust of potential participants.

Obtaining informed consent

We found that obtaining written informed consent could be complicated by differing norms, concerns, and expectations across cultural groups about signing documents. In 1 of the 2 Somali groups, the women did not understand that the purpose of the consent was assurance of voluntariness before participating, and they expressed concern about signing the form before experiencing the research. A lengthy discussion ensued, resulting in a reduced focus group length, and ultimately the group decided to provide written consent only after the focus group discussion was finished.

Social scientific research in settings where informed consent is not appropriate or advisable (eg, in situations where being identified could result in participants’ arrest or worse) has resulted in growing awareness by research ethics boards that, even in North America,

verbal consent might be both appropriate and more comprehensible to participants.¹⁰ Where participants are unfamiliar with research and focus groups, extra time should be allotted for discussing written consent and its alternatives.

Sensitive and innovative data collection approaches

To ensure that the research setting was informal, relaxing, and welcoming, most of the focus groups were held at the local immigrant resettlement office, a setting that is familiar to many immigrant groups in Hamilton. Participants affirmed that a culturally appropriate meal and provision of on-site child care by a known member of the community increased their comfort level and signaled that we recognized that many participants were busy wives and mothers whose time, as well as insights, were valuable. We had expected participants to be shy owing to the nature of the topic and the conservative cultures and religions of some groups; however, the women in all groups displayed an unexpected amount of interest, enthusiasm, and willingness to share experiences.

We developed a focus group plan (ie, interview guide or list of topics, questions, and probes, plus activities and materials) that incorporated interactive hands-on activities designed to help participants comfortably engage with the topic of discussion. Field-testing the guide with the Canadian-born group helped us to modify our plan. At the suggestion of field workers, instead of directly questioning participants, we used indirect questioning (eg, "Imagine you have a friend, [common name], who comes to you with some questions about her health. What do you think your friend would know, do, or think about [topic]?"). We also incorporated 3 interactive activities: drawing and labeling reproductive organs on a blank female form on a flip chart as a group, viewing and discussing a videotape showing a conversation between a female physician and a patient contemplating a Papanicolaou smear, and handling and discussing a vaginal self-sample kit for human papillomavirus testing.

The anatomy labeling exercise provided context for discussing cervical screening. Although shy at the beginning, the women in each focus group later became quite animated, joking and teasing one another about their drawings and labels: "That uterus is too big," said one woman. Another replied, "Yes, but this woman has had 6 children already!" This activity helped "break the ice." It also revealed that some women do not know any specific words for *cervix* in their native languages, and that anatomic terminology greatly varies across dialects. We learned that it was important to ensure that the women and field workers understood exactly what was being discussed by providing appropriate descriptions rather than assuming common knowledge from the use of a single term. By doing so, the terminology used by

the women could be incorporated into culturally relevant non-English audio and print educational material.

Developing a standardized video, which was used in all groups, demonstrated that such a methodology was acceptable across all groups and useful even for a sensitive health topic. Using additional activities (eg, drawing, videotape, and self-sampling kits) stimulated intensive discussions in all groups, demonstrating the usefulness of different tools to engage the groups.

We learned from field workers that immigrant women want information about cervical screening and related health concerns that they are not receiving from their regular health care providers. To respond to their needs within the research process, we added a postinterview "doc talk"—a question-and-answer period with a female physician. The physician also provided some basic information about cervical health and cancer prevention. Women were very engaged in and appreciative of this part of the group meeting. In fact, the venue proved a missed opportunity to provide services, as several participants indicated that they would have liked to have had Pap smears done right away.

Overall, the focus group process and activities were embraced by women across all groups. This is in keeping with emerging findings that focus groups are a uniquely appealing and effective approach for engaging people from culturally and linguistically diverse backgrounds.¹

Managing budget and time requirements

Multilanguage research requires sufficient funds and time. For example, the cost of translation varies considerably, depending on how unique a language is within a given setting (eg, Spanish-speaking translators are easier to find and less costly to hire in Hamilton than Dari- or Somali-speaking translators are). We needed to balance methodologic rigour with costs for both translation and back-translation. It was prohibitively expensive to use a professional translation service (\$12000 for 1 professional translation), and we pursued alternative strategies and hired the field workers or bilingual university students to transcribe and translate the research materials and focus group discussions. The main limitation of our approach was the lack of back-translation to confirm the accuracy of the interview guide terminology and the final transcribed interviews. There was an advantage in terms of local cultural familiarity; similar to our study, Mann et al found that back-translating interview guides is best done by a person who is much like chosen participants.¹¹ Although fluent in the language of their groups, the field workers still encountered difficulties with the vernacular of different regions.

A number of studies have reported the need for flexibility in accommodating participants' availability and unexpected increases to timelines and budget.^{9,11,12} Our data collection was extended by approximately 12


months because each new ethnolinguistic group represented in some ways the start of a new process with respect to the need for cultural learning and adaptation of our approach and tools. In addition, the scheduling of groups was often delayed for key seasonal events, religious holidays, and at one time because of violent conflict in the home country of one group. As in the study by Mann et al, we also found that several follow-up and reminder calls by the research team were needed to ensure an adequate number of participants.¹¹

Given the complexity and time demands of the study, harnessing the energies of a group of researchers and community partners was important. More researcher and staff hours were needed to organize and conduct the immigrant groups than the Canadian-born group. The interdisciplinary research team was important in bringing varied and practical expertise to a complex project.

Conclusion

A number of innovative strategies were discovered to be essential to conducting a qualitative study with multiple ethnolinguistic groups. We have highlighted 5 areas of the research process where challenges were encountered, and described some successful approaches. Formation of an interdisciplinary research team, partnership with an agency serving the groups of interest, inclusion of members of the target ethnolinguistic groups, allowing a choice of language for discussion, and incorporating culturally acceptable and interactive activities during the focus groups were among the important factors. Challenges that we did not foresee included the slow pace of recruitment and data collection, changes to our desired methodology to incorporate cultural norms, and high cost of professional translation services in some languages. These challenges, which were not insurmountable, served to underline the need for flexibility and innovation in conducting community-based research with immigrant and ethnic minority populations.

Development of culturally appropriate strategies can enable family medicine researchers and health care providers to understand and meet the needs of diverse primary care populations. Our research approach provides guidance for doing research with multiple

ethnolinguistic groups, which can be applied in many content areas. 

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Acknowledgment

This research was supported by the Canadian Cancer Etiology Network and the City of Hamilton Public Health and Social Services (Public Health Research and Development Programme). We thank the Settlement and Integration Services Organization for their partnership.

Contributors

Drs Karwalajtys, Redwood-Campbell, Fowler, Lohfeld, Howard, Kaczorowski, and Lytwyn contributed to concept and design of the study; data gathering, analysis, and interpretation; and preparing the manuscript for submission.

Competing interests

None declared

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